

Patient participation in fundamental psychiatric genomics research: a Dutch case study

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Abstract

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Objective To analyse the results of an action research process, the aim of which is to involve patients in fundamental psychiatric genomics research, against theoretical backgrounds that formulate a Dialogue Model for patient involvement.

Background Mixed views continue to exist about the value, appropriateness and potential of involving consumers and patients in basic medical research. There is a need to learn from practical examples.

Design An action research process was set up to facilitate and stimulate the involvement of a Dutch patient organization and a family organization in a psychiatric research consortium.

Findings The premises and procedures of the Dialogue Model constitute good guidelines for involvement in fundamental research. However, the normative core features for patient involvement underlying the model prove problematic due to: (i) properties of complex psychiatric genomics research; (ii) the entanglement of subjectivity and basic psychiatric science; (iii) universal notions of citizenship and difficulties of delineating the patient in psychiatric genomics research.

Conclusion Interaction and dialogue among scientists, patients and family members are possible in fundamental genomics research. The best approach for involvement would seem to be based on the creation of common ground and an evolving dialogue, which the guidelines of the Dialogue Model can provide. The challenge here will be to create also a dialogue on the normative anchor points of the dialogue process and to identify and monitor power relations inherent in these (tangible) dialogues.

Introduction

There are mixed views about the value, appropriateness and potential of involving consumers and patients in basic medical research.¹ As one of the scientists in Barber's research explained: '*I see little or no role for consumers in my kind of*

laboratory-based fundamental research'.¹ However, studies and practical examples indicate that it is possible to involve patients and consumers in fundamental research. Rabeharisoa and Calton's study of the French Muscular Dystrophy Association (AFM) shows, for example, that patients and family can actually have 'power'

over the research.² Flinterman and colleagues give the example of the German patient group Pro Retina,³ and Novas of PXE.⁴

Like the respondent in Barber's research, most board members for the large scale, long-term Dutch research consortium GROUP (Genetic Risk and Outcome of Psychosis) considered patient involvement impossible; for one of them, it was 'new-fangled nonsense'. However, they were challenged by their main funder ZonMw, the Netherlands organization for health research and development, to involve patients as a prerequisite for funding. It thus happened that late one evening in the summer of 2006, a board member for GROUP called the chairperson of Anoiksis, a patient organization for people with schizophrenia. He proposed to pick her up at 6.30 the following morning so she could accompany him to a meeting during which an International Evaluation Committee would be assessing the research conducted by GROUP on behalf of ZonMw. One of the items to be evaluated was the participation of patients and their organizations in the GROUP research. Anoiksis had never before spoken to GROUP about their research, and therefore the chairperson considered the invitation inappropriate and impolite. She did not want to function as a token person for GROUP's evaluation on patient participation and kindly but firmly declined the invitation (For GROUP see <http://www.group-project.nl>; ZonMw, the Netherlands organization for health research and development, <http://www.zonmw.nl>; Anoiksis, <http://www.anoiksis.nl>).

After this incident Anoiksis and GROUP invited a social scientist to start an action-research trajectory on patient involvement. This article analyses the results of the action research process that aimed at facilitating and encouraging the involvement of Anoiksis and the family organization Ypsilon in the GROUP research consortium (Ypsilon, <http://www.ypsilon.org>).

The theoretical background to this analysis is formed by the core features for the involvement of patients in research formulated by Flinterman³ and Abma,⁵ and their Dialogue Model which was developed more recently in several

research agenda setting projects.⁶ Research into public involvement in science and technology from the area of social studies of science is also applied.⁷⁻⁹

We chose to use the Dialogue Model because it emphasizes democratic interaction between stakeholders. The primary aim is not to reach the highest level of control by patients, but to include all voices in a mutual learning process to reach an integration of various knowledge sources (scientific, experiential). The Dialogue Model strives towards sharing power, but acknowledges the political dynamics at play in scientific research and therefore seems to be a promising framework for patient participation in fundamental research. To deal with asymmetries between scientists and patients, an important procedure concerns the development of an agenda within a group with converging interests, after which interactions and negotiations start with other groups. This enables patients and other groups who do not yet have a voice in science to develop their own agenda without the interference of professionals.

Several core features constitute the normative framework for achieving democratic justice in health research with the Dialogue Model. They have been developed through an analysis of claims of patient organizations and also refer to Habermas' principle of 'ideal speech situation'. Flinterman states procedural elements (issues of concern of all stakeholders are to be addressed) and social settings (aiming at shared decision making between scientists and patients in a democratic sense). Abma elaborates: (i) research questions should be derived from patients' experiences; (ii) research should contribute to patient empowerment on a collective and on an individual level; (iii) research should be directed at the subjectivity of patients in a positive sense; (iv) patients should be partners in research; (v) research should be practically useful; (vi) patients should be informed about the results.⁵ These explicit normative anchor points are meant to direct the processes set in motion when applying the Dialogue Model.

The purpose of this article is to explore to what extent the guidelines of the Dialogue

Model can also be used to foster patient involvement in fundamental psychiatric research, using GROUP as a case example. The first question is whether the premises and methodological procedures of the Dialogue Model can be useful guidelines for patient involvement in psychiatric genomics research. The second question is to what extent the core features can be realized as normative anchor points within fundamental research.

The analysis indicates that while the premises and procedures of the Dialogue Model are promising for participation in fundamental psychiatric research, achieving the core features was problematic due to: characteristics of GROUP research and psychiatric genomics in general; the entanglement of subjectivity and science; and the question of who the patient is in this kind of research.

Design

Action research can be defined as a reflective process where social scientists co-operate with stakeholders to improve their practice. Change and understanding are therefore pursued at the same time. In most action research, the objects of research are also participative subjects.¹⁰

Once the International Evaluation Committee had identified the lack of patient participation as a weak point in the GROUP project,¹¹ the GROUP board decided, in 2007, to rectify this situation by setting up a *Patients involvement committee*. This committee comprised a member of Anoiksis, a member of Ypsilon, two GROUP board members, research assistants and two social scientists functioning as action-researchers. The committee steered the action research.

Interviews were held during this year-long research project, with scientists (18), and patients and family (16). A focus group (7 people) was held with members of Anoiksis on 'questions for research'. Ethnographic visits to GROUP research and conferences of Ypsilon and other sites were made; and a process was started with Ypsilon to inform family members about psychiatric genomics. These activities resulted in an action paper that was accepted by

the steering committee, the GROUP board, and Ypsilon and Anoiksis.

Characteristics of GROUP's fundamental research

The Netherlands organization for health research and development, ZonMw, allocated €4.2 million to the GROUP consortium in which a large number of university psychiatric departments and mental health service institutions are collaborating, and over 3000 individuals (patients and family members) are now included. Originally, GROUP was not set up exclusively as genomics research. ZonMw had wanted primarily to initiate a 'scientification' of clinical psychiatry, and scientists wanted to study the progression of non-affective psychotic disorders over prolonged periods and within large populations. But large databases of test results and blood samples that are to be used for years to come also provide an eminently suitable platform for genomics research – and this is precisely what happened later, for example, when GROUP embarked on a collaboration with genomics experts from the United States who were interested in the potential this large database offered. The decision was a very straightforward one for some members of the consortium. If you are already collecting data, then you might just as well take a little blood to include genes in the equation.

At the outset, GROUP psychiatrists had no common hypotheses for research, nor did they have much knowledge of genomics. GROUP scientists sometimes felt that they were being swept along by a rapidly developing research situation, as illustrated, for example, by the fact that the technology of genome-wide scans became available during the research process, opening up all kinds of new research possibilities. However, they had a hunch of what was *in* and where the money was. So these scientists seized the opportunity, which was at times exciting, and at other times, rather frustrating. Psychiatrists who so far had opposed one another's paradigms in psychiatric research (e.g. about the question as to whether psychiatric

disorders are brain diseases or lie on a continuum of 'normal' psychological problems) suddenly had to work together in one large project. GROUP genomics research started therefore with scientists conducting heated and technical discussions against a background of rapid international developments. This situation meant that some scientists were, for quite some time, wary of contact with the outside world – they hoped to overcome their differences before communicating their research to outsiders.^{12,13}

Scientists in genomics had initially been enthralled by the One Gene One Disease (OGOD) model, which predominated until around 2005. The discovery that Huntington's disease is caused by an abnormality in a single gene had fuelled hopes of glorious cures for other psychiatric disorders. Many people – both within and outside the scientific community – thought, optimistically, that it was only a matter of time before *the* genes responsible for schizophrenia would also be discovered. It was felt that a cure would present itself once the pathway taken by genes into malfunctioning brains had been mapped.¹⁴

The idea that there is a close link between genotype and phenotype has meanwhile been abandoned in all areas of genomics. Current thinking focuses on 'complexity'. The world outside the organism (i.e. the environment) has been found to have a crucial bearing on many phenotypic characteristics. The GROUP psychiatrists agree on that, but differ fundamentally as to the best way forward to address this complexity.^{12,13}

As a result, a large-scale, long-term national research consortium into psychiatric genomics came into being. However, the up-scaling continued, resulting in a globalization of the research, with important funding from organizations in the United States and collaborations with psychiatric research consortia throughout the world. It has now become clear that this globalization is a prerequisite for genomics research. Only through research in various, genetically different, large populations can relevant molecular effects for psychiatric and other disorders become visible.^{15,16}

The scientific process described above is messy, technical, and rife with debate and ongoing developments on an international scale. This raises the question whether the premises and guidelines of the Dialogue Model are also feasible in such a context and whether the core features can be applied in the dialogue as normative anchor points. This last issue appears to be problematic. In a clear cut research process research questions can be derived from patient's experience and in these circumstances, patients and scientists can develop a mutual understanding, and reach decisions following democratic procedures. And it is only in such a process that research can be practically useful.^{3,5} This last requirement cannot be met in fundamental psychiatric genomics research. However, this did not exclude dialogue and collaboration between scientists, family members and patients.

Initially, most members of the GROUP board were appalled at being required to share decisions with Anoiksis and Ypsilon and tailor their research to their subjective experiences. Patient and family member involvement was, in their view, only possible in a knowledge deficit model: the one possibility they had observed as being potentially feasible, was to inform patients and family members about the basics of psychiatric genomics research. They also considered an additional difficulty to be the fact that patients were affected by schizophrenia, and this meant that some scientists were wary of informing patients about complex subjects such as gene environment interactions.

However, part of the action research process changed this situation. Abma proposes that conversational interviews by a facilitator are an important method to start involvement of different stakeholders in research. We also used this method to start our action research process and concentrated on what patients and scientists wanted to *know* about schizophrenia.

It emerged from a focus group interview that members of Anoiksis would like researchers to address specific questions of family susceptibility. The result was a list of questions on the (genetic) aetiology of schizophrenia, including questions such as

Why do I have schizophrenia, and why doesn't my brother?

And:

Suppose my daughter is genetically susceptible to schizophrenia, how should I raise her, what are good and bad circumstances?

After presenting the agenda of patients and family to the scientists, they discovered that there was common ground in the questions posed by patients and scientists on the aetiology of psychiatric problems. This was a real eye opener for the scientists. The lived experience of schizophrenia apparently raised the same generally formulated inquisitiveness regarding its aetiology, as in the scientific domain. As a result, one scientist suddenly understood that he did not have to decide what was the 'good' knowledge that he had to bring to patients, but that there was a basis for interaction with patients for the exchange of information and discussion. As he said:

This is not about transferring my knowledge product; it is about an evolving process with patients and family members about all kinds of questions!

This conceptual shift among some of the scientists was an important step forward towards involvement: from a knowledge deficit model to an interactive dialogic model. The next stage of the action research resulted in practical recommendations for interaction, most of them in the sphere of communication and information by GROUP, but also in the collaborative sphere, like redesigning the GROUP website to make it accessible to a larger audience and using conferences for interaction with patients and family members and evaluating this interaction.

The steering committee agreed to all the recommendations, most of which have been put into practice. For example, a member of Anoiksis and a scientist from GROUP jointly organized a workshop about psychiatric genomics at a large public conference, and a facilitator was appointed by GROUP for half a day per week to foster dialogue.

The conclusion here is that the premises and guidelines of the Dialogue Model can be helpful in highly dynamic and politicized contexts like

fundamental research. In the case example, conversational interviews with different stakeholders have proven to be a good method to start involvement in fundamental research, particularly when these conversations concentrate on what stakeholders want to *know*. Through a structured process of interaction in which each stakeholder group could first develop their own agenda and then learn about the agenda of other stakeholders, a common ground was found. The dialogue among stakeholders that followed created a shift in the position of scientists and opened up possibilities for collaboration. However, the example does also demonstrate that certain core features were not relevant in this context. This means that they cannot be absolute; they also have to become subject of dialogue.

Subjectivity and concerns of patients and family members

One of the core features of the Dialogue Model is that research should be derived from patients' experiences and directed in a positive sense at their subjectivity. This feature formulates the necessity to invest time and energy in identifying and articulating issues of concern to patients to empower them for negotiation with other stakeholders.

The GROUP case, however, raises the question whether concerns and issues are always there, and whether the realm of patients' subjectivity and experiences exists separately from scientific developments, and that they constitute an essentially 'good' and justifiable starting point for shared decision making between scientists and patients and for empowerment.

Until the request made by ZonMw for Anoiksis and Ypsilon to be involved in the research of GROUP, these organizations had *not* formulated concerns or issues about genomics research, other than a wish to be kept informed. Patients and family members were very keen to receive information, as was also illustrated in the action research process by the substantial numbers of people attending the workshops about developments in psychiatric genomics. Patients and family members were

curious to *know* what is going on there because this knowledge *might* touch on a fundamental question in the formation of a patient's, and a family member's, subjectivity: '*This disorder: why now, why me, and how can I live with it?*'¹⁷ We now analyse one episode from the action research in more detail to illustrate how 'the need to know', scientific knowledge and subjectivity are all interlinked.

Ypsilon asked one of the action-researchers for permission to publish an article in their newsletter on developments in psychiatric genomics towards complexity, which she had published elsewhere.¹⁸ The researcher agreed. However, prior to publication, Ypsilon proposed reformulating the article so that it would be better tailored to the understanding and needs of its members. The proposed Ypsilon heading for the article became: '*We all dream that one day there will be a cure for schizophrenia and that the responsible genes will be found.*' Ypsilon also proposed altered explanations of complexity, of environmental influences and gene x environment interactions.

With these alterations, Ypsilon revealed an interest in hanging on to expectations raised by genomics prior to 2005. Complex genomics opened up challenging perspectives to Ypsilon members: siblings of people with psychoses share susceptibility genes and characteristics with their brother or sister; their risk of developing psychoses is elevated; and parents might also be carriers of risk genes. Moreover, the environment as a risk factor (pregnancy, migration, cannabis, possibly trauma) is again back in the limelight, evoking the 1970s where family relations were held accountable for the development of schizophrenia. Members of Ypsilon had felt comfortable with the biological theories that were in vogue in the 1990s, and initially strongly resisted scientific results that indicated in the late 1990s that siblings shared cognitive and social characteristics with their schizophrenic sibling. The Ypsilon journal at that time published a debate on the question whether families were all mad now, like the mad families in the days of psychoanalysis. Explanations from subjective experiences followed to demonstrate that the

behaviour of family members was completely normal (<http://archieff.ypsilon.org/schizofrenie/plein/hulp/nieuws/yn82/vollema.htm>, accessed 2 November 2009).

The concern of Ypsilon teaches us that family members' concerns and issues are intertwined with the scientific domain, and do not arise from a totally separate domain of subjectivity. On the contrary, family members', and patients' subjectivity is also embedded in, and created by, scientific discourses about psychiatric disorders. This finding is consistent with research into lay expertise as a product of particular medical and social histories, in which scientific developments can be traced back.^{19–21} In the case of Ypsilon, we saw that family members began to reject the psychodynamic theories of the 1970s as soon as the biological theories became available in the 1990s. The unilateral embracement of biological explanations for mental illness was considered a way out of the feelings of guilt, stigma and responsibility created by the earlier psychodynamic theories. Therefore, in the late 1990s, Ypsilon initially rejected research into similarities between siblings and their brothers or sisters with psychoses, and, with the rise of genomics, they favoured monogenetic research.

These Ypsilon issues do not necessarily function as a 'good' beginning for involvement aimed at shared decision making on research themes between patients and researchers. And it is difficult to envisage that GROUP's research questions could have been derived from subjective experiences of Ypsilon members who rejected research into similarities between siblings, as it is impossible to envisage monogenetic research after 2005. When, as in this case, subjectivity and basic scientific developments are linked, the question becomes: how do issues and concerns of patients and family members emerge, and how should they be addressed in interactions with scientists?

Callon and Rabeharisoa contend that concerns only emerge as an effect of socio-technical arrangements whose 'framings and overflows' trigger the appearance of groups concerned by the development and applications of the technologies.⁷ When there are no overflows or new

framings, there will be no affected groups, and no issues. According to Latour, this situation should be our ideal, as normal citizenship does not entail participation in the development of science and technology: 'Not having to participate should remain the ideal and is of course the most widely distributed response to calls for action'.⁸ Latour and others therefore qualify these calls for action as 'the somewhat hysterical requirements of 'people's participation in scientific and technical decisions'.^{9,10}

The results of the action research not only indicate emerging concerns as a result of new framings of schizophrenia, but they also point to a need to *know* about the disorder, and a need to be able to relate to this knowledge in dialogue with scientists. Fundamental knowledge on psychiatric disorders influences people's illness explanations and identities ('who am I', 'how can I make the best of it') and therefore people in patient and family organizations are actively using scientific knowledge to position themselves in the world. A dialogue with scientists on how to do this can then be instructive to all parties involved; patients learn to use the knowledge of the new genomics while scientists can learn on the relation between knowledge and the lives of patients. In the process subject positions of stakeholders (scientists, family members) can shift and create new realities that foster collaboration, and again dialogue.

This can also be seen in the case of the journal article on the complexity of genomics. In the 1990s Ypsilon expressed a concern that resulted from new scientific framings of schizophrenia – family members resisted this research because in the 1970s they had endured the stigma of being a 'mad family' responsible for the disorder of their relative. This created, and to some extent still creates, a barrier to involvement in basic genomics research. However, in this case, the concerns did not prevent, but engender a dialogue. As a result of an interactive communication process with the action-researcher, and following on from the workshops on developments in genomics, Ypsilon adjusted their views and in the end did publish the original article. Ypsilon needed the interaction (as opposed to just

information) with scientists to begin to understand the meanings of the new genomics and how this related to their subjectivity. The new framing of schizophrenia created shifts in illness explanations and identities, and Ypsilon members started to formulate new concerns and issues for dialogue. For example, siblings who began to consider themselves to be special subjects-at-risk, formulated questions about their daily lives in the workshops with scientists, e.g.: 'At what age will I no longer risk having psychoses?'

Will such dialogue on fundamental genomics research in psychiatry empower patients and family members? It is not possible to predict whether genomics research will in the case of an evolving dialogue be empowering and directed at the subjectivity of patients in a positive way. There are dreams and high hopes for the future, but the actual application of genomics is very low, and, in the case of psychiatry, absent. It is generally far from clear how genomics will transform the meaning and management of psychiatric disorders, as it is not clear whether patients will benefit from it, or which patients will, and which not.^{12,13,22} The results of genomics research are contingent, they are creating an unknown future with as yet 'unknown' psychiatric subjects. However, by being informed, and expressing their concerns and issues and entering into a dialogue with scientists from the perspectives of their daily lives, patients and family members can influence developments in genomics and co-create this future with scientists.²³ An important condition is that these dialogic processes are constantly screened as to how power operates within them (e.g. 'how is power organized when scientists and patients run a workshop together?'). Dialogue should therefore always imply a dialogue on power, and this is a delicate subject.²⁴

The patient in psychiatric genomics

The core features of the Dialogue Model imply that the patient is a clearly identifiable subject. They also imply notions of citizenship that include implicit norms for patient participation in deliberative processes.

Starting with the last issue: norms for participation can be physical and mental, as the following example from one of the interviews clarifies:

The chairperson of the patient organization suffers from a social phobia. We asked her to participate in our research meetings. She was not able to.

How, in this light, to view repeated expressions of distrust of GROUP by Anoiksis? This distrust seems fully justified on the grounds of the sad start to the collaboration. But at times it also seemed to be influenced by the 'tendency of people with schizophrenia to be a bit distrustful of people' as a member of Anoiksis explained. Deliberative norms for participation implicitly assume an argumentative rationality that was not always there, as can also be illustrated by the focus group interview with Anoiksis members, where one participant formulated questions in terms of 'hallucinations'.

I would like to know where the children are, and what they want from me, and why they are speaking to me all the time.

Of course, it was no option to discard this remark as irrational; instead, the focus group discussed what the implications were for fundamental research. Participation therefore also implied a dialogue that dealt with such differences in deliberative ways of doing and that allowed for different types of rationality to exist.

What is needed here is an understanding of citizenship as a normative condition, instead of an absolute one, in which the aim is to organize participation in society in accordance with every citizen's potential. For this reason, the starting point of involvement should also preferably not consist of general calls for equal partnership of patients and scientists in research, but of careful explorations of dialogic possibilities and the implied power relations.

A second problem here is that developments in psychiatric genomics on an international level complicate involvement defined as shared decision making between patients and scientists. The international dimensions of the project raise questions about who 'the patients' are in this case. Can a small Dutch organization be deemed

to adequately represent patient perspectives? Would democratization require involvement of patients on an international level, and how then to cooperate with them?

Thirdly, there is the more fundamental question of who the patient is. Family studies show that psychiatric disorders as set out in the Diagnostic and Statistical Manual of Mental disorders (such as schizophrenia, bipolar disorder and schizoaffective disorders) commonly occur concurrently – or 'cluster' – in families. Research also suggests that there may be genetic overlap between the 'different' disorders.²⁵ This engenders the suspicion that the distinctions between these disorders are not as concrete as had previously been supposed. So 'who is the patient' in the case of the GROUP research? Is it the patient with schizophrenia, but also patients with anxiety, depression, and bipolar disorder? And maybe also the siblings of these patients, as their genetic susceptibilities construct them as possible future patients? As the prevalence of psychiatric disorders is high, these groups together represent a very substantial part of the population.

Therefore, *the* patient in psychiatric genomics can only be a relative notion. This is not really a problem when the aim of involvement is dialogue, because dialogues can be organized with different groups and stakeholders and can lead to different outcomes without any problem.

Conclusion

The analysis of the action research process that aimed to involve Anoiksis and Ypsilon in the psychiatric genomics research of GROUP shows how scientists wrestled to translate obligations into practice, and how patients and family members searched for ways to gain some control over the research. The requirement of ZonMw to involve patients in research created high expectations, blunders and tension. One might be tempted to agree in this case with Latour when he speaks of 'the somewhat hysterical requirements of 'people's participation in scientific and technical decisions'. But in that case, one would bluntly overlook what the action

research clearly shows: that involvement in basic research is possible as well as sought after by scientists, patients and family members. Therefore, the question was and is: how best to pursue and frame this involvement?

The premises and methodological guidelines of the Dialogue Model also proved in this case of fundamental research to be an effective start for interaction. However, the core features that functioned as normative anchor points underlying the Dialogue Model proved inconsistent with: (i) properties of psychiatric genomics research because of its long term time frame, complexity, and constantly changing developments; (ii) the entanglement of subjectivity and basic psychiatric science on the aetiology of disorders; (iii) universal notions of citizenship and difficulties to define who exactly is *the* patient of genomics research. Therefore, these core features should not be treated as absolute norms, but as conditions that have to be discussed and become part of a learning process in a specific context.

The action research process started with the creation of common ground among patients, family members and scientists. In the case of basic medical knowledge touching on aetiologies of (psychiatric) disease, people (patients, family members but also others) are concerned to *know* about developments in fundamental research, as these developments can have implications for who they think they are and who they can be in daily life. Anoiksis' questions about schizophrenia and genomics created common ground because (for scientists unexpectedly) they corresponded with the general formulation of questions in the scientific domain. Ypsilon members' subjectivity appeared to be influenced by a rejection of aetiological hypotheses that could increase feelings of guilt and shame. This called for a careful dialogue about new complex genomics. A dialogue, linked to the way family members create their subjectivity, and that in the process changed this subjectivity. For scientists, the formal obligation of the funding organization was transformed in a self-responsible motivation to involve other stakeholders in their research.

After such common ground was created, multiple and tangible plans could be made for future dialogue and collaboration. Evaluation of these dialogues between Ypsilon, Anoiksis and GROUP tend to comply with Habermas' normative horizons of communicative actions. According to Habermas, these horizons of power-free communication can never be fully achieved; they function as a counterfactual ideal against which practices can be evaluated and adjusted. In this specific case, the abstract Habermasian ideal seems a better foundation for a fruitful dialogic approach than one based on the normative anchor points of the Dialogue Model that have until now be formulated. However, as soon as such anchor points also become a topic for Habermasian dialogue, progress can be made with regard to patient involvement in fundamental research. Analysis of other cases will have to give an indication of the possibilities and limitations of such an approach.

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